Need for Expansion of Coverage for Narrowband UVB Phototherapy in Mycosis Fungoides and Sézary Syndrome

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Cutaneous T-cell lymphomas (CTCLs) are a group of non-Hodgkin lymphomas caused by mutations of T-cells within the skin.[1] The most common forms of CTCL include mycosis fungoides and Sézary syndrome.[1]

Mycosis fungoides and Sézary syndrome exist on a spectrum and are characterized by T-cell abnormalities manifesting as persistent, progressive erythematous patches, plaques, or tumors in predominantly sun-protected areas of the body.[1] Sézary syndrome is distinguished from mycosis fungoides as a malignancy of circulating central memory T-cells with skin-homing properties, whereas mycosis fungoides is a malignancy of cutaneous resident memory T-cells.[2]

The risk for acquiring CTCL increases with age.[1] The median age at diagnosis of mycosis fungoides is 58 years.[3] The prevalence of mycosis fungoides in the United States is between 5.2 and 6.6 per 100,000. Including all stages of disease, patients with mycosis fungoides are expected to live approximately 18 years from the time of diagnosis.[3]

To date, there is no cure for mycosis fungoides or Sézary syndrome. Effective therapies for these malignancies are limited, despite the burden of disease. Early in the disease course, skin-directed therapies are more effective than systemic treatments.[1] One of the most effective skin-directed therapies is narrowband ultraviolet B (UVB).

Narrowband UVB has been used for the treatment of mycosis fungoides for approximately 50 years.[4] The clinical response rates for patients with mycosis fungoides range from 54.25% to 91% with narrowband UVB phototherapy, which has an excellent safety profile.[4-7] In addition, the use of narrowband UVB phototherapy may slow disease progression and prolong patient overall survival.[8]

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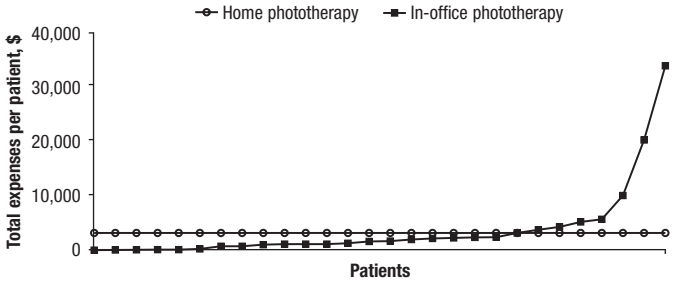
Figure Home versus In-Office Phototherapy Total Expenses for Each Patient with Mycosis Fungoides and/or Sézary Syndrome (N = 28)[a]



[a]The cost of home therapy was $3200, based on the cost of the Daavlin 3 series cabinet narrowband ultraviolet B home unit.

A key aspect of narrowband UVB phototherapy is maintenance therapy after remission, to prevent disease relapse.[9] As a result, patients and insurers face the economic burden and inconvenience of ongoing in-office treatment. Home phototherapy is a cost-effective solution; however, obtaining insurance coverage for home units is a barrier for many patients, including Medicare beneficiaries, despite being the age-group that is the most often affected by mycosis fungoides and/or Sézary syndrome.[1,3]

Currently, Medicare only covers home phototherapy units for patients diagnosed with psoriasis. However, the documented benefits seen with home phototherapy in the treatment of patients with psoriasis also exist for patients with mycosis fungoides or with Sézary syndrome, which include cost-savings, as well as good safety and efficacy.

Our Clinical Experience: Case Study

We have conducted an analysis of 28 patients with mycosis fungoides and/or Sézary syndrome over a period of 10 years between February 2008 and February 2018 at our institution, which showed that the average number of phototherapy treatments per patient was 55, with a mean cost per clinic visit of $67.38, and a mean overall cost of $3910.08 per patient, which well exceeded the cost of an at-home UVB unit of $3200 per patient (**Figure**).

Several patients who responded to therapy discontinued treatment prematurely, because they had transportation difficulties and expenses associated with in-office phototherapy that were not covered by insurance and presented excessive burden to the patients.

The average distance a patient traveled from home to the clinic for each treatment was 18.8 miles, with an approximate travel cost of $168.24. One patient required 495 treatments, with an estimated total cost of $33,910.88. Based on the 1-time cost of a home unit, this patient would have saved $30,710.88 in medical expenses for her mycosis fungoides and Sézary syndrome therapy with at-home treatment. Our data suggest that Medicare coverage of home therapy units would help to reduce significantly a patient's economic burden and improve patient ouctomes.

Cost-savings in this case also apply to the healthcare system in general. From 2000 to 2015, the utilization rate of phototherapy services billed to Medicare, with the majority being for UVB therapy, increased at an annual rate of 5%.[10] Within the same period, inflation-adjusted Medicare spending increased by 13% annually.[10] With the expected rise in the incidence and prevalence of mycosis fungoides and Sézary syndrome, we can expect a rising demand for phototherapy services.

We therefore argue that, similar to psoriasis, cutaneous lymphomas, which are rare, potentially fatal, and disproportionately affect the elderly, should meet the same criteria used for psoriasis for the coverage of home phototherapy units by Medicare, particularly when very few treatment options exist for patients with these chronic, incurable malignancies.

Furthermore, common pharmacologic treatments for mycosis fungoides, such as mechlorethamine gel, have an average monthly cost of $4000 per 60-g tube, and bexarotene capsules have an average monthly cost of $22,000.

Further studies comparing the relative cost of Medicare-covered pharmacologic therapies for mycosis fungoides, such as mechlorethamine and bexarotene gel, versus home phototherapy units should be investigated.

Author Disclosure Statement

Ms Kim, Ms Insley, Dr West, and Dr Woodworth Goff have no conflicts of interest to report.

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